Rehabilitation after brain injury

Headway
the brain injury association

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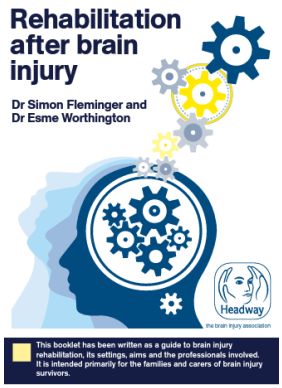
People directly affected by brain injury can receive limited free copies of Headway print booklets by contacting the helpline on 0808 800 2244.

*print copy may contain minor differences due to revision of content



Introduction

Once a person with a brain injury is medically stable and any physical injuries

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have been treated, they may be ready to be discharged from the hospital, or 'acute care' setting. However, many of these individuals are likely to experience complex, longer-term physical, cognitive and behavioural problems, which require a period of rehabilitation.

Unlike most other cells in the body, brain cells do not regenerate when they are destroyed. However, this does not mean that no recovery can occur. The brain is somewhat flexible and is able to reorganise itself, to an extent, in order to regain lost function. This is known as brain plasticity. During recovery, other areas of the brain take over the activities of the damaged areas and new nerve pathways can be established using undamaged 'spare' brain cells. Engaging in activity helps these alternative pathways to develop.

Rehabilitation aims to help the brain learn alternative ways of working in order to minimise the long-term impact of the brain injury. Rehabilitation also helps the survivor and the family to cope successfully with any remaining disabilities.

Accessing rehabilitation

There are many rehabilitation services across the UK, run by the NHS or private firms. Choosing which rehabilitation unit to refer someone with a brain injury to should involve the clinical team, the patient and their family. Once a referral has been made, the rehabilitation unit will usually carry out an assessment to make sure their service is suitable.

Availability and funding for places varies. However, most units, including private ones, accept NHS referrals and will be funded by the NHS. Other possible sources of funding include local authority social services, medical insurance, compensation claims and self-funding.

It is important to ensure that whoever is likely to have to fund the rehabilitation is aware that a referral has been made. The rehabilitation service will not be able to accept an admission until funding has been authorised. Many services accept referrals from outside their own area, but there are often limited places available

and long waiting lists. Specific details about the referral process, funding options and availability of places will be available from the unit.

Taking up a rehabilitation placement is an important commitment, and it is wise to explore all the options, visit different rehabilitation settings, and ask as many questions as possible before a placement is confirmed.

Rehabilitation settings

Rehabilitation occurs in the following settings. Most rehabilitation units provide one or more of these services:

- **Post-acute rehabilitation**: Intensive specialist rehabilitation for people who are not yet ready to return home after discharge from hospital. Neurological rehabilitation centres provide an ideal setting for further treatment, with a structured rehabilitation programme in place throughout the day.

- **Rehabilitation back into the community**: Following an inpatient rehabilitation stay, some patients may be transferred to a residential transitional living unit. Here the patient will develop their independent living skills so that when they leave they are able to live in a place of their own. Other patients will go straight back to their homes, with community rehabilitation teams or outreach teams helping them to make further progress; this may involve therapists coming to visit the person in their home or hostel.

- **Outpatient rehabilitation**: Some patients may be well enough to return home and receive further treatment as an outpatient, either at a local hospital or at a separate rehabilitation centre.

- **Slow-stream rehabilitation**: Some patients who no longer require intensive post-acute rehabilitation may still not be ready to return home. These people

may require long-term residential care.

Severely injured patients may still have the potential to make continued progress, even several years after the injury, although this may be slow. Therefore, it is important that their rehabilitation is not cut short. Many brain injury residential care units provide what is known as ‘slow-stream rehabilitation’ and if somebody with a brain injury can potentially benefit from this approach it is important they are given the opportunity.

What if no rehabilitation has been provided?

If your relative has been discharged home without any access to rehabilitation, and you have reason to believe that they would benefit from it, there are still options available.

You are perfectly within your rights to actively seek rehabilitation services, even if you have been told that there are none available or needed. The first thing to do is discuss the matter with your relative’s GP and/ or consultant.

You can also contact rehabilitation services directly. Our Headway helpline can provide information on specialist brain injury rehabilitation centres across the UK.

You can find a directory of rehabilitation services across the UK on the Brain Nav - The National Brain Injury Service Directory website. It is advisable to contact several units and visit them to assess their suitability before making a decision.

Headway Approved Provider Scheme

Headway has developed the Approved Provider scheme, an accreditation scheme appropriate for NHS and independent care settings, including hospitals and rehabilitation units, residential care homes, nursing homes and respite facilities specialising in ABI.

The units on the Approved Provider list have been assessed against standards devised by Headway to ensure they provide appropriate specialist care for brain injury survivors with complex physical and cognitive impairment. Further information and a list of Approved Providers can be accessed at www.headway.org.uk.

Timescales for recovery and rehabilitation

In the first month or two after a severe brain injury, it is only possible to guess at the length of time that recovery will take and the likely outcome. All that is certain is that recovery is a slow process and will take months or years rather than weeks.

Six months after the injury the picture will be clearer, but it is wise to wait until about a year after the accident before making any important decisions regarding the future. After a year or so one can be reasonably certain about the eventual degree of physical recovery. However, psychological recovery can take considerably longer and it is usually the cognitive (thinking), emotional and behavioural problems that cause longer-term difficulties, particularly for family members.

People do sometimes talk about there being a limited 'window' for recovery after brain injury, for example, that recovery ceases to take place beyond two years. However, this is now known not to be the case and people may actually continue to improve for a number of years after brain injury. Indeed, many people say that they never stop regaining the skills that they lost following the injury.

Nevertheless, the greatest visible progress does occur in the first six months or so post-injury and after this improvement is often less obvious.

Factors which may affect the rate of the person's recovery include:

- Type, severity and location of the person's brain injury
- Age (younger adults tend to do better)
- Pre-injury health
- Pre-injury personality, intelligence and lifestyle
- Social support from family and friends
- Other issues, such as alcohol or drug misuse

Depending on the individual's specific difficulties and their potential for recovery as assessed by rehabilitation staff, a programme of rehabilitation may last for a few weeks or may continue for months or years.

The rehabilitation team

In a specialist rehabilitation setting, a ‘multidisciplinary’ team of professionals will work closely with the person with a brain injury.

Initially, each therapist will carry out detailed assessments to explore the extent of the difficulties caused by the brain injury, including physical, cognitive, emotional, behavioural and social difficulties.

Following the assessment process, the team will discuss with the client and the family what their priorities and goals for the period ahead might be and what they hope to achieve. Based on this, the rehabilitation goals - both short and long-term - will be agreed and the rehabilitation programme will be planned. In devising the rehabilitation programme, the team will want to set goals that take into account each patient’s individual views and needs, their cultural background, and pre-injury lifestyle and interests.

The different therapists who may be involved in the rehabilitation process, and their areas of expertise, are outlined next:

Clinical neuropsychologist

A clinical neuropsychologist is a psychologist who specialises in the assessment and treatment of behavioural, emotional and cognitive (thinking) problems following brain injury. A neuropsychologist can advise on how to build upon the person’s existing skills and abilities and how to reduce some of their difficulties.

Occupational therapist (OT)

OTs help people to develop independence in carrying out daily tasks such as dressing, washing, cooking and leisure activities. An OT will also help the person to develop the skills that underlie these activities, such as budgeting and planning, and help to find ways around any remaining problems. At a later stage, the OT may help and advise on difficulties that may be encountered in the home environment and advise on any adaptations that may need to be made. They will also be involved in planning for returning to work. There are OTs working within

both the NHS and social services.

Speech and language therapist
A speech and language therapist (sometimes referred to as a SALT or SLT) helps people to improve their communication skills. This may include understanding and expressing both written and spoken language and improving speech clarity. The speech and language therapist will work with family members to help the person to communicate as best they can in their daily life and will identify any communication aids that may be helpful. They may also be required to assess swallowing difficulties and provide guidance on how this should be managed safely.

Further information on this subject can be found in our publication *Coping with communication problems after brain injury*.

Physiotherapist
A physiotherapist helps people to regain the use of their muscles and joints after injury and helps with balance and movement problems. A 'physio' will, for example, suggest exercises to help the person improve their physical ability and enable them to become as mobile and independent as possible.

Nurse
Nurses help the therapists to implement many of the rehabilitation strategies. In many in-patient rehabilitation units the care provided by the nursing team is the foundation for the rehabilitation programme provided by the multidisciplinary team. On in-patient units and in the community there may be specialist nurses who take on specific roles, such as the management of epilepsy or behavioural programmes.

Social worker
Social workers provide practical advice on issues such as benefits, housing, transport and assistance at home. They are also trained to offer emotional

support to individuals and their families.

Case manager

A case manager is responsible for overseeing and managing the overall care of the person with a brain injury. They will prepare an individually-tailored care plan or treatment programme for each client, which is designed to meet the person's specific health, social and emotional needs. Case managers can come from a variety of professional backgrounds, such as social work, occupational therapy, or nursing. Brain injury case managers are usually only available through private referrals and interim compensation payments.

Family members

Family members have a very important role to play in helping the survivor make as full a recovery as possible. A good working relationship between the family and the rehabilitation team is essential in making sure that rehabilitation programmes are followed correctly. Research suggests that the patients who make the best recovery are those whose family is actively involved and can maintain the skills learned in rehabilitation once the patient has gone home.

Sometimes relatives will need to learn new skills so that they can help to provide the best support. However, it is important that the family member does not become a 'therapist' and that they are encouraged to focus primarily on their role as somebody who provides love and affection. Family members are usually invited to participate in formal meetings with staff members to keep them informed of their relative's progress. Sometimes the family will need to act as an advocate for the survivor when the survivor lacks the capacity to make decisions for themselves.

There are many rehabilitation professionals working in private practice. If little or no rehabilitation has been provided by the NHS or social services then one option can be to contact professionals independently. It may still be possible to obtain an NHS or social services referral, or it may be necessary to pay privately.

Psychological recovery

A wide variety of cognitive, behavioural and emotional problems can occur after brain injury and may impact significantly on work and family relationships. Even after minor injury some people have persistent problems for months or even years.

Problems may not be immediately obvious after the injury, but may become apparent some weeks or months later as the person engages in more activities. Nevertheless, particularly for those with severe injuries, slow but steady improvement tends to occur in psychological symptoms over a period of months or years.

Many cognitive, behavioural and emotional problems can be helped by treatment from a clinical neuropsychologist. For example, if problematic behaviours develop after brain injury (such as verbal or physical aggression, or inappropriate sexual behaviour) behavioural modification programmes may be used to raise the patient's awareness of their behaviours and encourage more appropriate responses.

Cognitive rehabilitation may also be used to help improve attention, memory, and language abilities. Finally, various psychotherapy approaches may also be used, such as cognitive behavioural therapy (CBT), which help patients to learn to cope emotionally with their disabilities and to re-establish meaning in their life.

Returning to work

Once the person is able to look after their personal needs, to travel around from place to place and to manage social contacts reasonably well, they may be able to consider returning to work. This will depend largely on the degree of recovery that has been made, what the person's previous job was and what employment opportunities may now be available.

For those with less severe injuries, return to work within a few weeks or months is often achievable. However, it is important not to rush back to work too quickly. If this happens, some problems that had seemed to be resolved may reappear. The

person may, for example, suddenly find that their concentration or energy levels, which seemed fine at home when convalescing, are not as good as they thought.

It is often wise to look at a phased return to work, so that the way in which the person is coping with the transition can be gently tested out. Some people will be able to return to their old job, while others may need to consider a less demanding role.

A period of retraining may be required and adaptations to the workplace may be needed. Ideally, a specialist brain injury vocational rehabilitation service will be able to provide assessment and rehabilitation programmes that will enhance the potential to return to work. Vocational rehabilitation involves professionals such as neuropsychologists and occupational therapists, who can help people to understand the type of work they can now do and support them to achieve their goals.

Only a small number of specialist vocational rehabilitation services are available, although many units and community brain injury teams provide similar services. The Headway website provides details of the services available in the UK and information in the '*Accessing rehabilitation'* and '*What if no rehabilitation has been provided?*' sections of this publication also apply to these services.

If the injury has been very severe, the person may not be able to return to paid employment. In this case, it is important that a plan is worked out to give the person a regular, satisfying way of spending their time. Access to leisure activities, social interactions and other meaningful activities such as volunteering will be important to provide structure in their life, as well as a sense of purpose and achievement. Local Headway groups and branches, as well as social services day centres and other voluntary and statutory sector organisations, may be able to provide facilities to accommodate these needs.

Support for families

The various difficulties that can occur after brain injury, in particular behavioural and emotional problems, can have a big impact on family members. There may

well be additional social or financial difficulties for the family, and relatives may need as much help and support as possible.

Studies have shown that family support and counselling are needed, not just in the early days but for a long time afterwards. The children of a brain injured parent can also be easily overlooked. It is very important that the relatives acknowledge the difficulties they are experiencing and ask for help when they need it.

The GP is normally the first point of contact, who, in turn, may advise seeking help from a clinical psychologist, social worker, counsellor, or others as appropriate and available. Local Headway groups and branches, and the Headway helpline can also be useful in supporting both the person with the injury and their relatives and friends.

Clinical guidelines

The following guidelines have been produced in order to improve rehabilitation services for adults with acquired brain injury and their families and carers.

- British Society of Rehabilitation Medicine (2009). BSRM *Standards for Rehabilitation Services, Mapped onto the National Service Framework for Long-Term Conditions.* London: BSRM, 2009.

- Royal College of Physicians and British Society of Rehabilitation Medicine. *Rehabilitation following acquired brain injury: national clinical guidelines* (Turner-Stokes, L., ed). London: RCP, BSRM, 2003.

- Royal College of Physicians, British Society of Rehabilitation Medicine and Department for Work and Pensions. *Vocational assessment and rehabilitation after acquired brain injury: inter-agency guidelines* (Tyerman, A. & Meehan, M., eds). London: RCP, BSRM, 2004.

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As a charity, we rely on donations from people like you to continue being able to provide free information to those affected by brain injury. To donate, or find out how else you can get involved with supporting our work, visit www.headway.org.uk/get-involved.

If you would like to leave feedback for this publication, please consider completing our short survey at www.surveymonkey.co.uk/r/hwpublications or contact us at publications@headway.org.uk.

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